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Comparison of the Inventory for Client and Agency Planning and the Supports Intensity Scale

**Poster Presented at the 137th Annual Meeting of the
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Purpose

Scores from the Inventory for Client and Agency Planning (*ICAP*) are combined with other measures to determine the Individual Budget Amount (IBA) for Wyoming adults funded by the Medicaid Home and Community Based Services (HCBS) Waiver. In some cases, providers request budget amounts greater than what the IBA formula predicts the person should require. The Wyoming Department of Health - Developmental Disabilities Section (hereafter referred to as the DD Section) has no additional instruments to determine the validity of requests for additional budget allocations. The Supports Intensity Scale (*SIS*) may provide additional information to assist the DD Section to more accurately estimate budget needs, including rate setting and resource allocation. The purpose of this study is to compare the *ICAP* and *SIS* results for selected Adult DD Waiver recipients in an effort to understand the relative advantages of the *SIS* in determining support needs.

Background

In 1988 the state of Wyoming began using the *ICAP* (Bruininks, Hill, Weatherman, & Woodcock, 1986) to characterize the functioning level of people with developmental disabilities served by community providers as well as the Wyoming State Training School (Heinlein & Fortune, 1995). By the late 1990s the *ICAP* was being used to establish an individual's eligibility for Medicaid Waiver Services and to guide funding decisions. The *ICAP* followed a trend originated by the developers of the AAMD Adaptive Behavior Scale (Nihira, Foster, Shellhaas, & Leland, 1974) by including not only an index of adaptive behavior in their measure but also an index of problem behavior. The thinking was that positive competencies to adapt are balanced by behavior that bothers others or represents maladjustment and that both dimensions may limit personal success and community participation (Meyers, Nihira, & Zetlin, 1979). The *ICAP* yields an overall score that is a combination of these two indices recognizing that limitations in daily functioning could result from lower levels of adaptive behavior and higher levels of maladaptive or problem behavior. At the time of its development, the *ICAP* was unique in that it also included a Service Level Index score [a weighted composite of the adaptive behavior (70%) and problem behavior (30%) portions of the *ICAP*] that purportedly measured the relative *overall* intensity of supervision and/or training that a person might require. Although the *ICAP* was not developed to support rate determination and resource allocation, the Service Level Index Score has been used for that purpose by several states (Smith & Fortune, 2006).

Strengths and Limitations of the *ICAP*

The *ICAP* has a number of strengths, summarized most recently by Smith and Fortune (2006). These attributes include: strong psychometric characteristics (reliability and validity) for measuring adaptive and problem behavior, broad normative sample (early childhood to adulthood), straightforward administration and scoring, and sensitivity to differences among individuals with varying degrees of behavioral functioning. Beyond the standardized data obtained from the *ICAP*, the measure also compiles demographic information, diagnoses, and other information relevant to determining service needs.

Nearly three decades have passed since the *ICAP* was developed. During that time there have been dramatic changes in the lives of persons with intellectual disabilities (Braddock, 2002). For example, improved educational opportunities and methods to facilitate behavioral functioning have enhanced readiness of persons with intellectual disabilities to participate in the community. Resources previously allocated to institutions are now being directed to community services (Braddock, 2002). The community inclusion movement has gained considerable traction since 1986 and, as a result, more people with intellectual disability are living independently and maintaining competitive employment – something that was exceedingly rare for earlier generations. The current cohort of people receiving support services is much more independent and better prepared than cohorts who were already in their 20s and 30s when the *ICAP* was developed (Thompson et al., 2004). One could reasonably question whether the *ICAP* normative data are representative of the current population of people with intellectual disability.

The *ICAP* is also out of step with current conceptualizations of service delivery. The measure was designed when the prevailing view was that service delivery was based on a person's independent functioning level (i.e. without help or supervision) – a so-called deficit approach. The lower the person's adaptive functioning and the higher their maladaptive behavior, the more services were provided. In contrast, the contemporary view favors support-based measures which focus on the amount of support that a person needs to function successfully (Brown, Ouellette-Kuntz, Bielska, & Elliott, 2009). In short, the *ICAP* does not directly assess support needs – rather support needs are inferred from the obtained scores. Measures like the *SIS* are consistent with current trends and are designed to measure extraordinary support needs.

The content of the *ICAP* does not fully reflect the skill sets associated with community inclusion. The adaptive behavior portion of the *ICAP* includes Motor Skills, Social and Communication Skills, Personal Living Skills and Community Living Skills. Each subscale consists of 18-21 items presented in order of developmental acquisition. While

many of the individual items remain appropriate, some items lack a context of social and community participation. For example, there are no items related to the use of technology (personal computers, iPads or iPods, cell phones, or other assistive technologies) to support social and community participation. Moreover, the *ICAP* lacks any assessment of employment, health and safety, or life-long learning activities that can affect service needs.

Similarly, the *ICAP* was developed at a time when providers were more concerned about property destruction and aggressive behavior than other forms of problem behavior. As a result, the weighting of these behaviors in determining the General Maladaptive Index score was greater than the weighting associated with the other problem behaviors included in the *ICAP*. In an era in which community placement is the goal for all people with intellectual disability, one could argue that the *ICAP* categories of disruptive, socially offensive, and uncooperative behavior might also warrant higher weightings. Moreover, particularly concerning behaviors, such as suicide attempts, sexually inappropriate behavior, substance abuse, and wandering are either absent or afforded lower weightings in determining the *ICAP* Service Level Index score.

In summary, the *ICAP* was developed at a time when traditional services ruled the day. Community inclusion and supported employment were just beginning to gain a foothold. As a result the *ICAP* items are not an adequate reflection of life in the 21st century for people with intellectual disabilities. A paradigm shift has occurred in which a deficit-based approach has been replaced by a supports based approach to service delivery. Although the *ICAP* has a number of strengths, it does have clear limitations in the current context regarding supports and services.

Supports Intensity Scale

“The Supports Intensity Scale (SIS) was developed ... in response to changes in how society views and relates to people with disabilities. ...Chief among those changes are those related to: (a) positive expectations for the life experiences of people with disabilities, (b) the use of functional descriptions of disabling conditions, (c) the focus on chronological-age-appropriate activities, (d) the emergence of consumer-driven services, and (e) the provision of individualized supports through a supports network (p. 1, Thompson et al., 2004).”

The *SIS* has three sections. **Section 1** assesses Supports Needs in six areas or subscales: Home Living, Community Living, Lifelong Learning, Employment, Health and Safety, and Social Activities. Each subscale is composed of 8-9 activities and the individual is rated on three aspects of extraordinary support (i.e., support beyond that which is typically needed by most individuals *without* disabilities) in each targeted activity. Informants provide ratings on the **type of support** (none, monitoring, verbal/gestural

prompting, partial physical assistance, or full physical assistance), the **frequency of support** (ranging from none or less than monthly to hourly or more frequently), and the **daily support time** (ranging from none to 4 hours or more) for each activity.

In contrast to adaptive behavior scales that assess specific skills that a person has learned, the *SIS* assesses the “extraordinary support that a person needs in order to participate in the activities of daily life (Thompson et al., 2004).” For example, in the Home Living Section, the item “Bathing and taking care of personal hygiene and grooming needs” includes all activities that take place with regard to personal care and grooming such as showering, getting into and out of the tub safely, brushing teeth, washing hair and body, hair care, being clean throughout the day, changing clothing, obtaining haircuts, and performing nail and skin care. Individuals are rated on the whole of bathing and taking care of personal hygiene and grooming needs and not on any one part.

Scores obtained from **Section 1** include: raw scores, standard scores and percentile scores for each of the six activity subscales as well as the overall *SIS* Support Needs Scale. The standard scores and percentile values are derived from a standardization sample of adults with intellectual disability. Higher standard scores and the associated percentile scores reflect greater support needs. For example, a person with a *SIS* Support Needs percentile score of 45 indicates that 45% of individuals have less support needs than the person (or that 55% would have greater support needs).

Section 2 of the *SIS*, the Supplemental Protection and Advocacy Scale, includes eight areas that are rated on the same dimensions as **Section 1** – namely the Type of Support, Frequency of Support, and Daily Support Time required. The eight areas of Protection and Advocacy are: advocating for self, managing money and personal finances, protection from exploitation, exercising legal responsibilities, belonging to and participating in self-advocacy/support organizations, obtaining legal services, making choices and decisions, and advocating for others. Raw scores are calculated for each of the 8 items – summing the frequency, daily support time and type of support ratings. The raw scores are ranked from highest to lowest and the highest four are transferred to the Supports Intensity Scale Profile page. **Section 2** is not used to determine the *SIS* Support Needs Index. However, it does provide potentially useful information for developing individual support plans.

Section 3 of the *SIS* addresses Medical and Behavioral Support Needs. The developers of the *SIS* reasoned that “certain medical conditions and challenging behaviors can dictate that an individual will require substantial levels of support, regardless of his or her relative intensity of support needs in other life-activity domains assessed in Section 1 of the *SIS* (p. 34).” The Medical Support section includes 16 specific support needs organized in four categories: Respiratory Care, Feeding Assistance, Skin Care, and Other Exceptional Medical Care needs (e.g., protection from infectious diseases, seizure

management, lifting and transferring). **Table 1** includes a listing of the *SIS* Medical Support Needs. Each item is rated on a 3 point scale (No Support Needed =0, Some Support Needed=1, or Extensive Support Needed=2). The ratings for the 16 items are summed. If the total score is larger than 5 and there is at least one item endorsed as “Extensive Support Needed”, then “it is highly likely that the individual has greater support needs than others with a similar *SIS* Support Needs Index score.” The information provided in this section is unique to the *SIS*, as the *ICAP* and similar measures do not address Medical Support Needs.

The Behavioral Support Needs portion of **Section 3** includes 13 items grouped in four categories: Externally Directed Destructiveness, Self-directed Destructiveness, Sexual and Other (e.g., wandering, substance abuse, and other serious behavior problems). A listing of the *SIS* Behavior Support Items is provided in **Table 2**. Unlike measures such as the *ICAP*, the focus of this scale is assessing the degree of support necessary to *prevent* the occurrence of challenging behaviors (or *maintenance* of mental health supports) rather than the frequency and severity of the challenging behavior. Nonetheless, there is some correspondence in the behaviors included the *SIS* and the *ICAP* reflected in **Table 2**. There is clear overlap for aggressive behavior, property destruction and self-injurious behavior (highlighted in green) and potential overlap for four additional behaviors (highlighted in yellow) in which the *SIS* behavioral item is included in a broader behavioral category in the *ICAP*. The *SIS* addresses six additional areas of behavioral support need that are not represented in the *ICAP* (highlighted in orange). The Behavior Support Needs are rated using the same categories as the Medical Support Needs section and similarly scored. That is, each item is rated on a three point scale and a total score is calculated. If the total score is greater than 5 and at least one item is rated as “Extensive Support Needed” then “it is highly likely that the individual has greater support needs than others with a similar *SIS* Support Needs Index score.”

In summary, the *SIS* is designed to guide the development of person-centered plans by measuring the frequency, intensity and type of support that an individual needs to function on an everyday basis in the community. Rather than measuring deficits in behavioral functioning, it provides a direct measure of extraordinary support needs. Smith and Fortune (2006) caution that because “the *SIS* does not measure adaptive or maladaptive behavior per se... (It) is not directly comparable to tools such as the *ICAP*.” Moreover, the *SIS* addresses areas, such as employment related supports and medical support needs, that are not covered in the *ICAP*. The *SIS* is designed for adults ages 16 and older. A childhood version of the *SIS* is currently in development. High levels of inter-rater reliability are achieved by skilled interviewers with extensive training on the *SIS*. Administration by an impartial third-party reduces potential conflicts of interest when funding is linked to assessment results.

The Current Study

With the cooperation of the Wyoming Department of Health - Behavioral Health Division, Developmental Disabilities Section, WIND conducted a study to compare the results of the *ICAP* with those obtained from the *SIS* for 15 adults with extraordinary utilization needs being served on the DD Waiver. These individuals were selected for the study by DD Section staff. There were 4 males and 11 females aging in range from 23-65 years ($M=39.6$). The *SIS* respondents included support staff, service coordinators, and relatives. The client was present for a portion of the assessment in some instances but most of the 15 clients did not participate. The *SIS* assessments took approximately an hour and half, although some lasted 2 hours or more. The *SIS* assessments were scored and then compared to the most recent Inventory for Client and Agency Planning (*ICAP*) assessment; the time interval between the assessments averaged 16.6 months.

There was a considerable range among the *ICAP* Service Scores – from 6 to 74 for these adults. The results can be summarized as Limited personal care and/or regular supervision ($n=1$), Regular personal care and/or close supervision ($n=7$), Extensive personal care and/or constant supervision ($n=5$), and Total personal care and intense supervision ($n=2$). Recall that the *ICAP* Service Score is a 70/30 blend of adaptive and maladaptive behavior portions of the measure. In several instances, the lower *ICAP* Service Scores were the result of low levels of adaptive behavior and high levels of problem behavior. With the exception of two participants the *ICAP* Broad Independence Domain scores and associated age equivalent scores were below the 5 year level. Adopting a criterion of -20 or lower, the *ICAP* Maladaptive Behavior scores of 4 of the participants were moderately serious to serious.

In comparison, 14 of the 15 participants had *SIS* Support Needs Scale results above the 50th percentile (**Figure 1**) – indicating above average support needs. In fact, 10 participants had scores at or above the 75th percentile. Again, these scores reflect support needs in Home Living, Community Living, Lifelong Learning, Employment, Health & Safety, and Social Activities. It is apparent that the highest *SIS* Support Needs scores are not always associated with the lowest *ICAP* Broad Independence Domain scores (the portion of the *ICAP* that most closely approximates the *SIS* Support Needs Scale). The Pearson correlation coefficient between these scores was not statistically significant ($r = -.25$). **Figure 2** presents a scatterplot of these scores. This finding is consistent with the results of Thompson et al. (2004) and Wehmeyer, Chapman, Little, Thompson, Schalock and Tasse (2009). Specifically, the *SIS* Support Needs Scale is measuring a different construct than adaptive functioning, as defined by the Broad Independence Domain of the *ICAP*.

Twelve of the fifteen participants met the criteria for Exceptional Behavioral Support Needs on the *SIS*. Ten or more participants required behavioral support regarding

the prevention of assaults or injuries to others (n=13), tantrums or emotional outbursts (n=12), wandering (n=11) and property destruction (n=10). Fourteen of the participants required support to maintain mental health treatments. The value added by the *SIS* with regard to Behavior Support Needs is evident in prevention of wandering (n=11), prevention of other serious behavior problems (n=4 for obsessing, being manipulative and verbally aggressive, dialing 911 on a telephone when not appropriate and choking, regurgitation), prevention of suicide attempts (n=3), prevention of sexual aggression (n=3), and prevention of substance abuse (n=1) as well as maintenance of mental health treatments (n=14). It is also highly likely that stealing (n=9), pica (n=3), nonaggressive but inappropriate sexual behavior (n=8) and prevention of tantrums or emotional outbursts (n=12) may have been endorsed for the *SIS*, but not the *ICAP*, given differences in how the behavioral items are structured in the two measures.

It is possible to compare the *ICAP* Maladaptive Index scores and *SIS* Behavior Support Needs for the entire group by comparing the number of participants identified with exceptional scores. Adopting an *ICAP* Maladaptive Index score of less than -20 and the criteria described above for the *SIS* Behavior Support Needs scale, 4 participants had exceptional scores on the *ICAP* and 11 did not. In contrast, 12 of the participants had exceptional scores on the *SIS* Behavior Support Needs scale while 3 did not. In summary, while 4 participants were identified by both measures, the *SIS* Behavior Support Needs scale identified 8 additional participants with exceptional behavior support needs that would require consideration in service planning.

Six of the participants had Exceptional Medical Support Needs. The most frequently endorsed needs were: Therapy Services (n=11), Other Medical support needs (n=10 for scheduling dental and eye appointments, hearing aids, pain management, wheel chair maintenance, dental hygiene, skin breakdown/cleansing, and acid reflux), Dressing of Open Wounds (n=9), Seizure Management (n=5) and Inhalation or Oxygen Therapy (n=5). However, when individual Medical support needs were endorsed by respondents, the most frequent rating was “extensive support.” In summary, six of the fifteen participants met the criteria for exceptional Medical Support Needs. Given that medical support needs are not assessed by the *ICAP*, this represents value added for the *SIS*.

Summary

The *Supports Intensity Scale* provides conceptual and practical advantages over first generation measures like the *Inventory for Client and Agency Planning* for estimating budget needs, including rate setting and resource allocation. These advantages include:

- The *SIS* provides a direct assessment of extraordinary support needs and therefore is ideally suited for the person-centered planning process.

- The *SIS* Support Needs Scale examines the support that a person needs in order to participate in the activities of daily life in measureable terms (type of support, amount, and frequency).
- The broad range of activities considered in the *SIS* Support Needs Scale has greater relevance for community inclusion than adaptive behavior scales that assess achievement and performance in specific domains. For example, the *SIS* includes employment, health and safety, and life-long learning activities that can affect service needs.
- The *SIS* is the only measure of its type that captures information related to Medical Support Needs.
- The Behavioral Support Needs portion of the *SIS* has a clear emphasis on the effort needed to prevent the occurrence of problem behavior rather than characterizing it in terms of frequency and severity. Moreover, it assesses a broader range of difficult behavior, many of which have clear implications for community inclusion.
- Assessment of support needs in relation to a standardization sample provides a stronger basis for resource allocation, especially when combined with Extraordinary Behavioral and Medical Support Needs. However, it may be necessary to supplement the *SIS* with additional information, such as type(s) of disability, presence of certain conditions, and other demographic/situational factors (Smith & Fortune, 2006).

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Distribution of SIS Index Scores

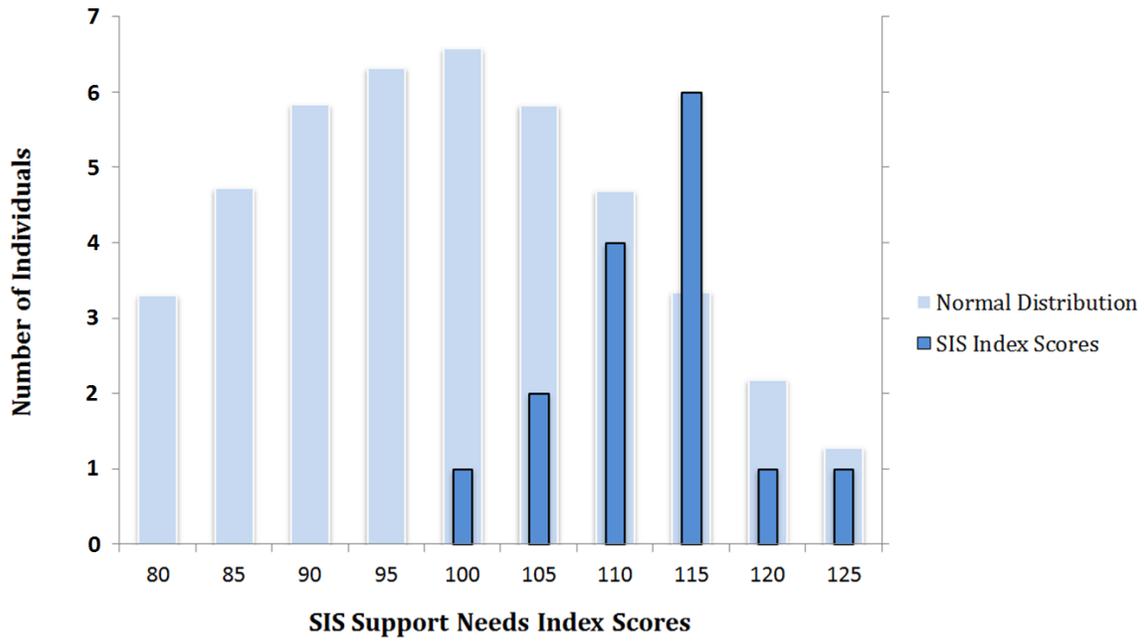


Figure 2 - Correlation Between ICAP and SIS Scores

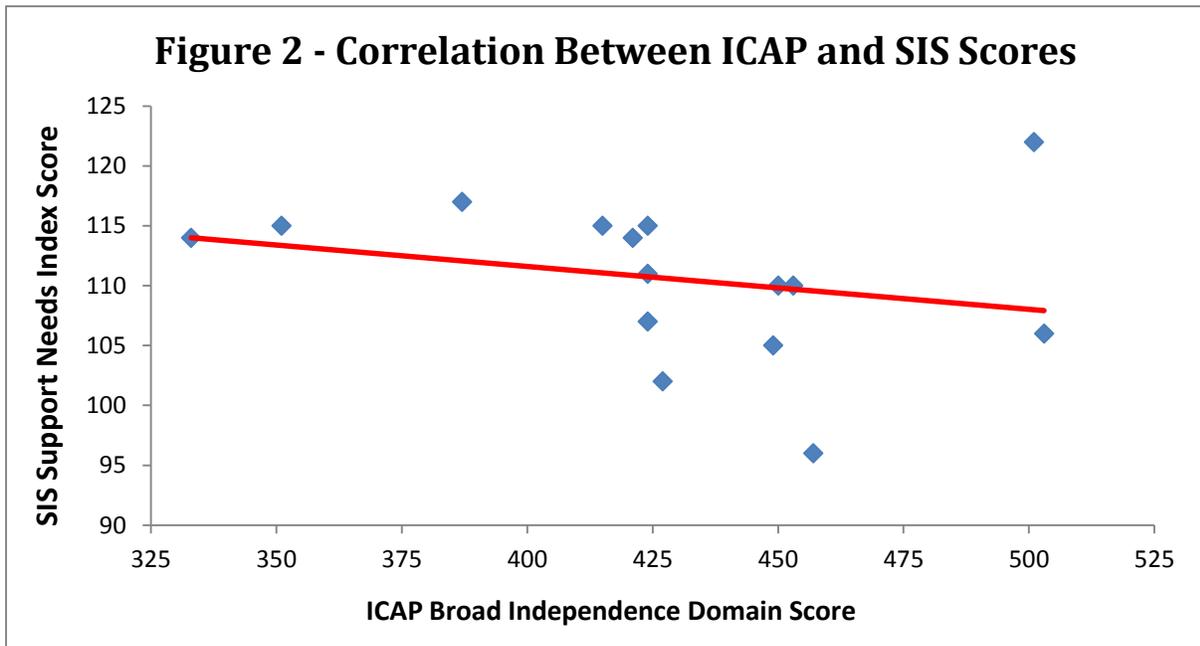


Table 1 – Supports Intensity Scale: Medical Support Needs

Number of Participants with this Support Need	
Respiratory Care	
Inhalation or oxygen therapy	5
Postural drainage	0
Chest PT	0
Suctioning	0
Feeding Assistance	
Oral stimulation or jaw positioning	0
Tube feeding	0
Parenteral feeding	0
Skin Care	
Turning or positioning	1
Dressing of open wounds	9
Other	
Protection from infectious diseases due to immune system impairment	2
Seizure management	5
Dialysis	0
Ostomy care	0
Lifting and/or transferring	2
Therapy services	11
Other(s) – specify:	10

**Table 2 – Supports Intensity Scale:
Behavioral Support Needs**

Behavioral Support Need	Number with this Support Need	Overlap in Content⁵
Externally directed destructiveness		
Prevention of assaults or injuries to others	13	SIS and ICAP
Prevention of property destruction	10	SIS and ICAP
Prevention of stealing	9	SIS and ICAP ¹
Self-directed destructiveness		
Prevention of self-injury	9	SIS and ICAP
Prevention of pica	3	SIS and ICAP ²
Prevention of suicide attempts	3	SIS only
Sexual		
Prevention of sexual aggression	3	SIS only
Prevention of nonaggressive but inappropriate sexual behavior	8	SIS and ICAP ³
Other		
Prevention of tantrums or emotional outbursts	12	SIS and ICAP ⁴
Prevention of wandering	11	SIS only
Prevention of substance abuse	1	SIS only
Maintenance of mental health treatments	14	SIS only
Prevention of other serious behavior problems	4	SIS only

¹Included as a specific example on the ICAP Uncooperative Behavior item

²Included as a specific example on the ICAP Unusual or Repetitive Behavior item

³Included as a specific example on the ICAP Socially Offensive Behavior item

⁴Included as a specific example on the ICAP Disruptive Behavior item

⁵The ICAP Withdrawal or Inattentive Behavior item does not correspond to any of the SIS Behavioral Support Needs

